Alzheimer's Disease Demonstration Grants to States Program: North Carolina's Project C.A.R.E. – Caregiver Alternatives to Running on Empty

"Implementing Systems and Sustained Change in Long-Term Care" Executive Summary

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EXECUTIVE SUMMARY

The Alzheimer's Disease Demonstration Grant to North Carolina is a partnership among the Division of Aging and Adult Services in the North Carolina Department of Health and Human Services, the Duke University Center for Aging Family Support Program, the Western Carolina Chapter of the Alzheimer's Association, the Mecklenburg County Department of Social Services, and the Area Agencies on Aging for Regions B, C, F and I.

The grant funds Project C.A.R.E. (Caregiver Alternatives to Running on Empty), which has created a community-based, family-centered service system that provides direct access to dementia-specific respite care and connects families to other long-term care services. Project C.A.R.E. targets an underserved rural, minority and low-income elderly population. It demonstrates that both public and private entities can deliver dementia-specific respite services, allowing communities to administer the program in a way that is best-suited to local circumstances and needs.

Project C.A.R.E. offers families a personalized approach to respite care. Through Family Consultants, families are offered in-home assessment and care planning, a simplified determination of eligibility, a wide degree of flexibility and choice in the use of respite funding, ongoing case management, and education and training for caregivers and respite providers. Family Consultants also serve as a link for families to other long-term care resources. Family Consultants develop networks of provider, governmental, and volunteer agencies to bring quality dementia-specific respite services to caregivers.

To achieve systems change, Project C.A.R.E.: has used a number of strategies:

- Integrated the needs of family caregivers into public programs and longterm care planning. Through cooperation in strategic planning and collaboration with other state programs serving caregivers at the state level and the work of the Family Consultant in building networks of agencies and providers at the local level, Project C.A.R.E. has helped create a state long-term care system that recognizes the needs and preferences of the caregiver as well as the person with dementia.
- Explored the efficacy of varying administrative sponsorship. Project C.A.R.E. has demonstrated its effectiveness in two different administrative settings: under the guidance of an Alzheimer's Association Chapter, and as part of a unified county social services agency.

- Increased access and availability of a comprehensive range and type of dementia-specific respite services by using the Family Consultant model. Under Project C.A.R.E., the Family Consultant develops agency partnerships, recruits and trains service providers, publicizes the availability of caregiver services, conducts in-home assessments, facilitates the connection between the caregiver and respite care options and providers, and provides continuing support to both caregiver and provider.
- Offered consumer choice and consumer-directed respite care. Project C.A.R.E. provides flexibility in meeting the caregiver's needs through individualized attention and multiple options in the type, scheduling, and staffing of respite services.
- Conducted outreach to low income, rural, and minority families.
 Project C.A.R.E. targets underserved rural, minority and low-income elderly populations. By developing personal contacts and building bridges to the faith-based community, Family Consultants have helped overcome the cultural and geographical isolation facing dementia caregivers in rural mountainous areas and urban minority communities.
- Connected families with information and services. Project C.A.R.E. is bringing the expertise of the Alzheimer's Association and other proven resources into the community arena, educating both caregivers and providers to techniques which produce a higher quality of life for both client and caregiver. The network development work of the Project C.A.R.E. Family Consultants also puts them and the project in a unique position to link caregivers to a wide range of long term care services and supports.
- Leveraged ADDGS funds for sustainability. The grant partners are making a diligent effort to identify resources to sustain the Project C.A.R.E., seeking private foundations funding, collaborations with other long-term care grants, and making plans to approach State legislative staff with evidence of the project's effectiveness. In the Mecklenburg County site Project C.A.R.E. has demonstrated its value to a local agency which is willing to support the Family Consultant function and be an advocate for county-level respite funding.

Through this Alzheimer's Disease Demonstration Grant, Project C.A.R.E. is a replicable model for bringing dementia-specific respite services and resources to family caregivers of persons with Alzheimer's disease and other dementias, with the flexibility to meet the needs of caregivers in different economic, cultural, and geographic settings.